NC Central Cancer Registry

EVERY CASE COUNTS
The Physician Office Reporting Project

Overview of the Practitioner's Responsibility to Report
January 2020

This document is intended to assist independent physician practices, ambulatory surgery centers and free-standing cancer treatment centers in NC in understanding their requirement to report, the importance of reporting, the types of cases required to be reported and the actions required to report eligible cancer case information to the NC Central Cancer Registry (CCR).

CCR staff will work individually with onboarded practices to provide detailed instructions and training for completing the cancer data abstract and meeting the reporting requirements.

Every year, thousands of North Carolinians are diagnosed with cancer.

The CCR was established in 1945 with legislation making cancer a reportable disease as of 1990.

All health care providers are **required by law** to report cases to the CCR (as in nearly all other states).

Cancer is a Reportable Disease in NC

What is the NC Central Cancer Registry (CCR)?

The CCR is a population-based reporting system that serves as the sole repository of complete cancer incidence data for the State of North Carolina.

https://schs.dph.ncdhhs.gov/units/ccr/

CCR Cancer Data At Work

- Provides an overview of all cancers diagnosed in NC.

- Used by cancer prevention programs, clinicians, epidemiologists, policy makers and the public to understand the impact of cancer among North Carolinians.

- Provides accurate data for public health policy-making and epidemiological research and investigation efforts related to cancer control efforts.

- Provides surveillance data to cancer prevention or early detection programs for targeting and evaluating cancer control.

- Supports efforts by community hospitals, health systems, and community-based cancer prevention programs by providing statistics on the distribution of cancer cases.

- Used by local and state public health officials to respond to public concerns.

- Used to help researchers identify and invite people to join research studies.

CCR Cancer Data At Work

- Used in national publications and statistics including:

    - United States Cancer Statistics (USCS), the official federal government statistics on cancer: https://www.cdc.gov/cancer/uscs/index.htm

    - American Cancer Society's Cancer Facts and Figures: https://www.cancer.org/research/cancer-facts-statistics.html

    - Cancer in North America (CINA): http://www.cancer-rates.info/naaccr/

Authority

- The CCR was established in 1945 by NC General Statute Chapter 130A - Article 7.

- In 1990, additional legislation was enacted by the General Assembly to clarify the responsibilities of the CCR. The CCR administrative rules are codified as NC Administrative Code Title 10A - Chapter 47 Subchapter B.

- The CCR has collected information about cancer in NC since 1990 and is a unit of the NC State Center for Health Statistics (SCHS) within the NC Department of Health and Human Services (DHHS).

- Since 1990, the General Statute has required hospitals, physicians, and certain other healthcare providers to report all diagnoses of cancer and other reportable neoplasms and conditions.

- As of 2013, House Bill 399 requires all facilities to report electronically (via cancer registry specific applications) to the CCR to increase efficiency and make cancer information available more quickly.

State Law

- The CCR operates by state law Authority G. S. 130A: 205; 130A-208 through 130A-213.

- Visit www.schs.state.nc.us/units/ccr/ for a copy of the NC State Law, House Bill 399 and Administrative Code.

- For more information regarding NC Legislation:
    - NC General Statutes: https://www2.ncleg.net/Laws/GeneralStatutes
    - NC Administrative Codes: http://ncrules.state.nc.us/ncac.asp
    - NC General Assembly: www.ncleg.net/Sessions/2013/Bills/House/HTML/H399v10.html

Required Reporting Timeline

Every reportable condition coming under the care of the reporting clinic/office are reportable as soon as possible but not longer than six months after the date of initial diagnosis (or within six months of first visit if the patient was not diagnosed at the reporting office).

Cases first seen in the office during the:	Must be reported by:
First quarter (January - March)	Oct. 1st
Second quarter (April - June)	Jan. 1st
Third quarter (July - September)	April 1st
Fourth quarter (October - December)	July 1st

Penalty for Not Reporting

- The Administrative Code states: "The CCR shall monitor the reporting of health care facilities and providers on a quarterly basis. If a health care facility or provider has failed to report at least 90 percent of its cases within six months of diagnosis, the registry shall notify the facility or provider in writing of that fact within 30 days and the facility or provider shall be given another 30 days, or up to 60 days for good cause shown, to fulfill its reporting requirement."

- "If a facility or provider is out of compliance for two consecutive quarters and is not demonstrating progress toward becoming compliant then the State Health Director shall direct the registry to collect the data and shall direct the facility or provider to reimburse the registry for all actual costs expended in order to obtain the data up to $100 per case abstracted."

Data Confidentiality

- CCR has procedures in place to assure the confidentiality provisions of the state law and HIPPA are implemented.

- Staff sign confidentiality agreements and data is kept in secured offices, workstations, applications and networks.

- Only aggregated data that does not reveal patient identity is released for published reports or to respond to general data requests.

- Researchers needing confidential data must undergo a stringent approval process.

- HIPAA does not change or affect the mandate for reporting cancer. The CCR is considered a Public Health authority and disclosure of protected health information to the CCR is permitted by HIPAA without patient signed consent. HIPAA federal regulations citation: 45 CFR 164.512.

Background of the Physician Office Reporting Project

The physician office reporting project officially began in 2007.

Since then, over 200 practices have been onboarded to report and ongoing recruitment continues today.

Background

- Traditional data collection has been primarily from hospitals.

- As medical advances have occurred, diagnosis and treatment of certain cancers has moved from the hospital/acute care setting to being fully cared for within the physician office/clinic.

- Receiving data from all sources in which patients may interact ensures that the CCR's case ascertainment is as complete as possible.

- Physician offices/clinics are a critical component of this reporting matrix.

Background

- Cancers commonly cared for outside of the hospital setting include:
    - Melanoma of the skin
    - Prostate cancer
    - Bladder cancer
    - Early colon/GI cancers
    - Early GYN cancers
    - Early breast cancers
    - Hematopoietic malignancies such as leukemia, polycythemia vera and myelodysplastic syndrome

Background

- The CCR developed a program to assist independent physician offices and free-standing treatment centers in complying with the public health law.

- Practice specialties that are the focus of reporting include dermatology, urology, surgical ambulatory centers, gastroenterology, cancer treatment centers, medical and radiation oncology and others that fully manage patients with cancer outside of the hospital.

Background

- The purpose of this concerted effort is to alleviate under-reporting or a delay in reporting which can adversely affect incidence rates and research efforts from incomplete data collection.

- Data collection of all cancer cases in NC is our goal and your participation will enable us to achieve a more complete set of data.

Getting Started

- Review the information in this document and on the CCR web site.

- Determine the approximate number of new cancer cases seen each year.

- Determine office staff responsible for reporting.

- Contact the CCR Physician Office Coordinator to begin the onboarding process.

- Work with your assigned CCR staff representative to set up training and obtain required reporting resources.

- Reporting will require some initial setup. Once that is done, regular quarterly casefinding and reporting requires only a few simple steps.

Required Resources

- The primary resource is the abstractor's time to complete the reporting activities. It is acknowledged that the responsibility for reporting might be assigned to staff of varying levels of medical experience, computer skills and time availability. The abstractor should have access to patient records, a computer with internet access and a work area.

- The CCR utilizes a few key resources for ensuring consistent and accurate data collection. All of these resources can be downloaded directly to your computer, accessed online, or will be provided by the CCR – at no cost.

- CCR staff will work closely with onboarded offices to ensure they have access to the CCR's data entry application and any additional resources necessary for successful reporting.

- CCR staff are always available answer questions.

Cases Required to be Reported

There are several criteria used to determine if a case is reportable. An overview of the types of cases required to be reported is provided on the following pages.

Onboarded offices will receive training and instruction along with more details on how to interpret and apply these criteria.

Cases Required to be Reported

- Cell Type / Histology - Any tumor, condition or diagnosis described as:
  - Malignant
  - Malignancy
  - Cancer
  - Carcinoma (adenocarcinoma, squamous cell carcinoma, transitional cell carcinoma, etc.)
  - Sarcoma
  - Melanoma
  - Lymphoma
  - Leukemia
  - Chronic myeloproliferative disorder/Myelodysplastic syndrome (see ICD-10 codes above)
  - Metastasis/Metastatic

Cases Required to be Reported

- Behavior Code - Any tumor, condition or diagnosis described as:
  - Invasive
  - Malignant
  - In-situ

- <u>All</u> tumors in the Central Nervous System (CNS) are reportable
  - Tumors arising in the CNS are the only benign tumors that are required to be reported
  - The CNS includes tumors (of any type or histology) in the:
    - Brain (C70.-)
    - Meninges (C71.-)
    - Spinal cord, cranial nerves, and other parts of the CNS (C72.-)
    - Pituitary gland (C75.1)
    - Craniopharyngeal duct (C75.2)
    - Pineal gland (C75.3)

Cases Required to be Reported

- Diagnostic Confirmation - Any tumor, condition or diagnosis determined by any of the following methods:
  - Histology - tissue examined by a pathologist and confirmed to be cancer
  - Cytology - fluid examined by a pathologist and confirmed to be cancer
  - Clinically - confirmed by other means such as radiology, laboratory results or the physician's impression.

Cases Required to be Reported – Special Reporting Requirements

- Intraepithelial Neoplasia, Grade III of the following sites only are reportable:
  - Anus (AIN III)
  - Vagina (VAIN III)
  - Vulva (VIN III)
  - Larynx (LIN III)
  - Squamous intraepithelial neoplasia, grade III (SIN III) of sites other than Cervix and Skin

Cases Required to be Reported – Special Reporting Requirements

- Skin and Genitalia
  - Lesions of the mucoepidermoid tissues of the lip or anus
  - Lesions of the skin or other tissues of the labia, clitoris, vulva, vagina, prepuce, penis, scrotum
  - Lesions of any site with any of the following histologies:
    - Dermatofibrosarcoma protuberans (8832, 8833)
    - Kaposi sarcoma (9140)
    - Malignant melanoma (8720-8790)
    - Merkel cell carcinoma (8247)
    - Mycosis fungoides (9700)
    - Cutaneous T-cell lymphoma (9709)
    - Sebaceous adenocarcinoma (8410)
    - Sweat gland adenocarcinoma (8400)

Cases <u>NOT</u> Required to be Reported

- Prostate Intraepithelial Neoplasia, Grade III (PIN III)

- Cervix Intraepithelial Neoplasia, Grade III (CIN III)

- Carcinoma in situ (CIS) of the *cervix*
  - CIS of the cervix is the only in situ cancer that is <u>not</u> reportable. All other in situ cancers <u>are</u> reportable.

- The following histologies of the skin (C44.-) are <u>not</u> to be reported:
  - Skin lesion is referred to only as: Neoplasm, malignant, malignancy or tumor
  - Carcinoma, NOS of the skin
  - Papillary carcinomas/adenocarcinomas of the skin
  - Squamous cell carcinomas of the skin
  - Basal cell carcinomas of the skin

- Patients with a history of cancer, and currently does not have active disease of that particular cancer, are not required.

- Patients with a diagnostic or surgical procedure (that produced a pathology report) for the reportable cancer at a facility with a CoC Accredited Cancer Program are not required as these will be reported by the CoC facility to the CCR.

Casefinding

Casefinding is a systematic method of identifying all potential cases to be reported.

It will identify reportable and non-reportable cases as well as cases that may have already been identified and reported.

Casefinding

- Most offices utilize cancer-specific ICD-10-CM codes to query billing data to identify all potentially eligible cases.

- A link to the most current list of cancer-specific ICD-10-CM codes can be found at: https://seer.cancer.gov/tools/casefinding/

- By querying on these specific codes, most eligible cases will be identified. For instance, most patients with a reportable diagnosis will have an ICD-10 code in the range of C00.- - D49.- in their billing record.

- Review of other reports and logs such as pathology reports, visit logs or treatment logs may also be necessary.

The Casefinding Process

1. Determine the casefinding reports that will be utilized.

2. Generate the list of potential cases from your billing data based on the required cancer-related ICD-10-CM codes.

3. Review reports to identify cases that need to be reported.

4. Submit reportable cases according to the reporting deadlines.

5. Keep track of cases identified for reference in future casefinding activities.

Type of Data Collected

Cancer registries collect information that will describe in detail the:

**Patient
Cancer Type
Stage at Diagnosis
Treatment at Diagnosis**

Type of Data Collected

Patient/Demographic

- Gender
- Race/Ethnicity
- Date of Birth
- Residency at Diagnosis
- Occupation
- Vital Status

Cancer/Tumor

- Diagnosis Date
- Site of Origin
- Histology/Cell Type
- Behavior/Invasiveness
- Grade
- Method of Diagnosis

Stage at Diagnosis

- Tumor Size
- Tumor Markers
- AJCC TNM (Extent of the tumor and involvement of lymph nodes and/or distant/metastatic sites)

Treatment

- Surgery
- Radiation Therapy
- Chemotherapy
- Hormone Therapy
- Immunotherapy

A complete list of data items and the purpose of each data item can be reviewed in more detail in the Cancer Collection and Reporting Manual (CCARM) on the CCR website at:
https://schs.dph.ncdhhs.gov/units/ccr/reporting.htm

The Data Submission Process

- Data Entry -

Physician office staff will utilize a free, secure, web-based database application called WebPlus to report required information about the cancer to the CCR.

The Data Submission Process

- WebPlus is developed and provided by CDC NPCR to the CCR. More information on WebPlus is available at: https://www.cdc.gov/cancer/npcr/tools/registryplus/wp.htm

- Access to WebPlus requires only internet access, an email account and a WebPlus account.

- Abstractors will need a work email address as this is how WebPlus communicates with users.

- WebPlus accounts will be setup by the CCR and provided to the abstractor when the office is onboarded.

The Data Submission Process

- WebPlus contains user-friendly data entry screens that are designed specifically for cases commonly seen in the physician office.

- After all data have been entered, the abstractor will save the abstract. The application will run through a series of quality checks to verify certain elements of the data.

- When the abstract is error free, the abstractor will release the abstract to the CCR.

- Once the abstract is released, no further updates to the abstract are required and the case is considered complete and submitted.

- All records are saved in the WebPlus database on a CCR secure server that has a digital certificate installed. Cases entered by one facility are not visible to other facilities.

Why are reporting requirements so strict?

- Data reporters are required to follow the reporting guidelines and must apply the coding instructions for each data item when abstracting cases.

- These reporting requirements follow national data standards to ensure the uniform description and reporting of neoplastic diseases.

- Proper classification is essential for clinicians and researchers to evaluate results of management.

- These requirements serve as the standard for reporting on the incidence and outcome of cancer to the healthcare community and the public.

Are data available to physicians?

- Absolutely! Reporting to the CCR can be beneficial to the reporting physician as well.

- Upon request, data from cases reported by a specific office can be stratified by various elements such as year, primary site, histology or stage for distribution to that office only.

- Aggregate data are also available on the CCR website at: https://schs.dph.ncdhhs.gov/data/cancer.cfm

- For other data requests, email the CCR Statistical Branch.

EVERY CASE COUNTS

Every person in North Carolina benefits from cancer research. With the help of facilities and practitioners like you, hundreds of research studies using information collected by cancer registries have helped us understand the causes of cancer and improve cancer treatment and outcomes.

Have More Questions or Ready to Start Reporting?

If you are an independent practice, clinic or center that diagnoses or treats patients with cancer, contact the CCR's Physician Office Coordinator to begin the onboarding process for reporting.

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